Inequity and Vulnerability in End of Life Care: Ethical Analysis

Yukiko Asada, Ph.D.

Department of Community Health and Epidemiology
Dalhousie University

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Inequity and vulnerability

- Popular words in health research and policy
  - Often used with ethical connotation but without precise definitions
  - Their relationship rarely discussed
Inequity

• Inequality ≠ inequity
  – Inequality = difference
  – Inequity = unfairness and injustice
    • Inequalities that are ethically or morally problematic

• Various definitions of inequity possible
• Precise definitions rarely defined
Vulnerability

• Implies special attention
• Examples of vulnerable populations identified:
  – Aboriginal peoples, immigrants, people with disabilities, homeless, high risk mothers, persons with AIDS, the mentally ill and disabled, alcohol or substance abusers, …
• “Subgroup approach” (Kipnis 2001, 2003): designating certain groups as vulnerable without examining its criteria and societal responsibility
  – Eventually, virtually everyone identified as vulnerable
  – Risk of stereotyping everyone in the group identified as vulnerable
Objective

• To clarify:
  – the meaning of inequity and vulnerability, and
  – their relationship

• Within the context of health care, end of life care, in particular
  – End of life care is often overlooked
  – Inequity and vulnerability in end of life care is virtually unnoticed
Risk chain model

- Developed by Alwang, Siegel, and Jorgensen (2001, 2002) for international development work
- Useful to understand how vulnerability occurs
Risk
Factors that increase likelihood of undesirable outcome

Risk response
Options to manage the risk

Outcome
Risk
Factors that increase likelihood of undesirable outcome

Risk response
Options to manage the risk

Outcome

Earthquakes
Driving
Abusive parents

Preparedness of the region and individual
Seatbelt laws
Child welfare programs

Emotional trauma
Physical illness
Injury
Death
Insights from the risk chain model

• Identifying the outcome of interest is a critical first step for defining vulnerability.

• Distinguishing risk and risk response avoid stereotyping the vulnerable.

• The risk chain model itself is empirical rather than normative.
**Risk**
Factors that increase likelihood of undesirable outcome

**Risk response**
Options to manage the risk

- Big party
- Limited amount of alcohol at the party
- Crack and Smash of glasses

**Outcome**
Being hit by lightning

Factors that increase likelihood of undesirable outcome

Do not play in bad weather

Options to manage the risk

Death in the golf course

Outcome
**Risk**
Factors that increase likelihood of undesirable outcome

- Being hit by lightening
- Being hit by the golf ball

**Risk response**
Options to manage the risk

- Do not play in bad weather
- Observe safety measures

**Outcome**
Death in the golf course
Ethically significant vulnerability

The vulnerable: those who are at risk of being treated inequitably
Ethically significant vulnerability

Risk
Factors that increase likelihood of undesirable outcome

Risk response
Options to manage the risk

Outcome

Inequity
• The risk chain model
  – offers a useful foundation upon which we examine vulnerability, yet
  – lacks an ethical component to guide judgments concerning what risks, risk responses, and outcomes are ethically problematic
Risk
Factors that increase likelihood of undesirable outcome

Risk response
Options to manage the risk

Outcome

Can people safeguard their own needs and interests adequately?

In what way does the outcome occur? (Some risks are ethically significant while others not)

Is the outcome ethically significant?
• What is the outcome?
  – Inadequate end of life care
• Is end of life care ethically significant? – Yes!
  – Norman Daniels’s normal species functioning view (1985, 2007)
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Risk response
Options to manage the risk

Outcome

In what way does the outcome occur? (Some risks are ethically significant while others not)

Can people safeguard their own needs and interests adequately?

Is the outcome ethically significant?
Risks of inadequate end of life care

• Choice
  – e.g., fully informed free refusal

• Unmet social obligation
  – Society fails to do something that it has an obligation to do
  – e.g., prejudice, lack of transportation, and complex system

• Nobody’s fault
  – Risks beyond our control (bad luck or biological mechanism)
  – e.g., dying with “orphan” diseases or an illness that requires complex care
Risks of inadequate end of life care

• **Choice**
  – e.g., fully informed free refusal

• **Unmet social obligation**
  – Society fails to do something that it has an obligation to do
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  - Risks beyond our control (bad luck or biological mechanism)
  - e.g., dying with “orphan” diseases or an illness that requires complex care
From ethical analysis of risks...

• End of life care is inequitable, when:
  – adequate end of life care is not offered, or
  – utilization or quality of end of life care is inadequate
    due to unmet social obligation or nobody’s fault

• The vulnerable are those at risk of being treated inequitably

• The vulnerable are, for example:
  – Persons with low socioeconomic status, disability, or minority status
  – Persons with illness requiring complex care or orphan disease
Risk
Factors that increase likelihood of undesirable outcome

Risk response
Options to manage the risk

Outcome

In what way does the outcome occur? (Some risks are ethically significant while others not)

Can people safeguard their own needs and interests adequately?

Is the outcome ethically significant?
• Some people “may be less able than others to safeguard their own needs and interests adequately” (Agency for Health Care Policy and Research 1998)
From ethical analysis of risk responses...

• End of life care is inequitable, when:
  – utilization or quality of end of life care is inadequate as a result of the lack of resources available to persons

• The vulnerable are, for example:
  – Persons with low socioeconomic status or minority status
  – Children
  – The severely mentally ill
Inequity

- Adequate end of life care is not offered,
- Utilization of or quality of end of life care is inadequate due to unmet social obligation or nobody’s fault, or
  - Persons with low socioeconomic status, disability, or minority status
  - Persons with illness requiring complex care or orphan disease
- Utilization or quality of end of life care is inadequate as a result of the lack of resources available to persons
  - Persons with low socioeconomic status or minority status
  - Children

Vulnerable persons
What this work adds

• The risk chain model:
  – prevents us from stereotyping persons with a group characteristic, and
  – allows us to investigate further heterogeneity among the vulnerable

• The extended risk chain model offers:
  – reasons for our intuitive identification of vulnerable populations, and
  – a language to discuss further what we mean by vulnerability and inequity
Questions and Discussion